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August 14, 2018

Green Mountain Care Board
144 State Street
Montpelier, VT 05620

Re: Comment on DRAFT Data Release Rule 7.000 and DRAFT GMCB Data Use and Disclosure Procedures Guide

Dear Members of the Green Mountain Care Board,

The Office of the Health Care Advocate (“HCA”) supports the Green Mountain Care Board’s (“Board”) efforts to revise its data release rules and, more generally, create responsive data governance policy. We also support the Board’s decision to clarify the data release rules with guidance so as to avoid issues related to the rules becoming obsolete due to technological change.

We have three specific comments related to the DRAFT Rule 7.000 (“Rule”) and the DRAFT GMCB Data Use and Disclosure Procedures Guide (“Guide”). Two of our comments relate to the need for clarification of the terms “other qualified institutional entity” and “good cause.” Our third comment relates to whether it should be mandatory for the Board to produce and release Public Use Data (“PUD”).

Clarification of “other qualified institutional entity”

Rule 7.301(a)(3)(b) specifies that the Board, when evaluating a request for Level 2 or 3 data elements or access to the Secure Analytic Environment, evaluate a Principal Investigator’s (“PI”) “affiliation with a university, private research organization, health care facility, state agency, or other qualified institutional entity.”

Many of the terms used in this section of the Rule have a plain meaning. For instance, a private research institution clearly includes entities such as RAND or RTI. However, it is not clear what an “other qualified institutional entity” is.

We recommend that the Board allow otherwise qualified persons to obtain VHCURES and/or VUHDDS data regardless of institutional affiliation and that the definition of “other qualified institutional entity” accord with this objective. The definition of an “other qualified institutional actor” should include, at the very least, advocacy and policy organizations and independent researchers. Such a broad definition of “other qualified institutional entity” would not unduly risk exposing data to unqualified persons as it would not alter the requirement that PIs have appropriate training, qualifications, and/or experience.

The Guide is likely the appropriate location of a definition of an “other qualified institutional entity.”

Clarification of “good cause”

Fee waivers are a necessary component to ensure access to VHCURES and VUHDDS data and we applaud the inclusion of this section in the Rule. Rule 7.401(f) specifies that the Data Governance Council (“DGC”) “may waive fees for agencies of the State of Vermont or for good cause shown.” We believe that the term “good cause” warrants further clarification. Such clarification would assist both applicants in crafting fee waiver requests and the DGC in ruling on fee waiver requests.

A definition of “good cause” should include a balancing of several factors, including but not limited to, the cost of producing the data, the applicant’s ability to pay for the data, the applicant’s organizations mission, whether the data will be used to benefit the public, and whether, if applicable, the proposed project’s work product will be publicly and/or freely available.

As what constitutes “good cause” may evolve over time, the inclusion of a definition in the Guide, as opposed to the Rule, is likely appropriate.

Production of a PUD

The HCA recognizes that significant resource constraints likely limit the number and scope of PUDs that the Board can produce and release. We believe, however, that the annual release of one or more PUDs affords the public access to important information about the Vermont health system. Further, such data could be used by the public to better understand and comment on Board regulatory functions including, rate review, ACO budget approval, and hospital budget approval.

We recommend that the Board alter the Guide’s language to mandate that the Board produce and publish at least one PUD per annum. We also ask that the publication date of this PUD be in Winter or Fall so that the public and other interested parties can use the PUD to inform activities related to the Board’s various regulatory processes that occur in the Spring and Summer.

Thank you for considering our comments.

Sincerely,

/s/ Eric Schultheis

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